

# NARRATIVE MATTERS



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## ‘I Don’t Want Jenny To Think I’m Abandoning Her’: Views On Overtreatment

*A palliative care physician helps a cancer patient cope with her coming death, while her oncologist struggles to give up treatment.*

BY DIANE E. MEIER

**I**n between seeing patients with the palliative care team at Mount Sinai Medical Center in New York City, I received from my secretary a message from someone seeking an office palliative care consultation. The patient, whom I’ll call Jenny, wanted to talk to me before she made an appointment, so I called her late in the day after the rest of the team had gone home. Jenny’s

voice was upbeat and cheerful as she told me how she had found me—from an Internet search—and why she had called. She was in her late fifties, a practicing clinical psychologist with a husband and a daughter recently graduated from college. She had been diagnosed with stage 4 non-small-cell lung cancer six years earlier.

When I heard this I wrinkled my brow. Nobody lives six years with this kind of

cancer, I thought to myself. Something’s odd here. Jenny wanted to see me to make sure her medical team was paying attention to what mattered most to her: her quality of life. There was nothing urgent; she was in no pain. We agreed to meet a couple of weeks later.

She came into the office with her husband, looking totally out of place amidst the frail geriatric population that we generally see in our practice. Elegant, slender, with a gorgeous head of curly blonde hair, Jenny was nothing like what I had expected. Her cancer story, too, was atypical.

She was diagnosed with cancer after experiencing a persistent cough. By the time she had a surgical removal of the tumor, the disease had already spread outside the lung. She then began chemotherapy and radiation at a major New York City cancer center. She became attached and grateful to the oncologist managing her treatment. Over six years she’d seen periods of remission during which she and her husband traveled the world, while maintaining her busy clinical psychology practice and raising their daughter. With each recurrence or progression of disease, her oncologist thought of a new approach to try, and each one worked. Her disease was stable, and her quality of life was good. She hoped she might turn this cancer into a chronic disease instead of a death sentence.

### What-ifs

Given how well Jenny appeared to be doing, I wondered why she was in my office. Jenny described herself to me as a “control freak”—someone who needed to know what to expect and what might happen to her. “Better to know and plan for the worst,” she told me. “That way I don’t have to worry about it.” Over the years she realized that her oncologist was unwilling—in her view, unable—to talk to her about the “What-ifs?” of her cancer. What if this next treatment doesn’t work? What if my disease progresses and I can no longer function the way I want to? What will that be like?

Illustration by Brett Ryder

Will I be in pain? Will I suffocate? How will my husband and daughter take care of me? Where and how will I die? What will I need? Healthy and happy as Jenny appeared, the uncertainty and the unknown were consuming her.

Her oncologist's reaction to each setback was to redouble his efforts to get the cancer under control. Her "What-ifs?" were met with, "We don't have to worry about that."

As a psychologist, Jenny eventually reasoned that her oncologist was unable to face the possibility—indeed, probability—that Jenny would die of this disease. So Jenny came to me, hoping I could give her some answers.

We talked about possibilities. Given the unusual course of her cancer to date, I admitted the real possibility that her oncologist could continue to find ways to keep it at bay. I explained that I could become a part of her treatment team to focus on her quality of life, provide the straight answers she sought, and participate in her desire to plan for the worst while continuing to hope for the best. She relaxed and smiled, expressing relief that her concerns had been validated and that a means of addressing them was in sight.

We talked about what she might expect as her lung cancer progressed, including increased fatigue and weakness, pain, and shortness of breath, and exactly how we could manage these. She wanted to know what it was like to die.

The natural dying process for a cancer patient—for any patient, for that matter—usually involves progressive fatigue, more and more time in bed or chair, more and more sleepiness, progressing to coma and a peaceful death. We talked about what the moment of death was like: slower and slower breathing, with pauses in between breaths, and during one of those pauses, she would die. She asked what would happen if she had pain and symptoms that couldn't be controlled. I explained that virtually all symptoms were manageable with palliative care. If necessary, there was the option of sedation, but it was quite unusual to need that. She followed my words closely and nodded her head, seeming relieved that she need not fear terrible suffering in her final days.

We talked about hospice and what it provides, which would include services



such as a team available to come to her home 24/7, as well as equipment, medicine, and training and support for her husband and daughter. If things ever got too difficult at home, she could go to an inpatient hospice setting with around-the-clock nursing and medical care.

Toward the end of our conversation, Jenny said she was worried that her oncologist would feel upset or hurt because she came to see me and that he might not be comfortable working with me on her care. I was worried about that, too. I offered to call him. I would make no treatment recommendations for her without talking to him first.

The relief on the couple's faces was palpable. Something huge and terrifying—and, to Jenny's oncologist, unspeakable—had been brought within her compass. Smiling and excited, Jenny shifted the conversation to talk about her book groups and what she was reading and writing. They left the office with a three-month appointment for follow-up.

With some trepidation, I called her oncologist and explained everything. To my relief, and that of Jenny and her husband, he agreed to work together with me on Jenny's care.

### The Disease Progresses

For the following eighteen months, Jenny received care from both her oncologist and me. We remained in regular e-mail and telephone contact. When she learned, several months after we first met, that her disease had progressed, the oncologist tried another experimental treatment to which Jenny re-

sponded well.

For another year, things remained stable, until Jenny began to feel increasingly tired and started to have difficulty focusing her attention and memory. Because of the memory lapses, she worried that she should no longer continue her psychotherapy practice. With her oncologist's agreement, we tried corticosteroids to reduce the swelling around the tumors in her brain and psychostimulants to improve energy and mood, which helped. She kept practicing but canceled a major trip and conserved her energy for home and work. She had no pain and experienced some shortness of breath but only when she ran for the bus or climbed a flight of stairs.

Several months after she first noticed the memory problems, she awoke with a headache and blurred vision. Brain imaging showed an enlarging mass that was progressing despite systemic chemotherapy and corticosteroids.

Jenny came to see me in the office to talk about this new reality. Her oncologist was recommending intrathecal chemotherapy, a treatment that involves placing a reservoir inside the brain in order to administer chemotherapy directly into the site where the tumor mass sits, in the hope of shrinking it. Jenny wanted my opinion on whether she should accept this therapy, but I was unfamiliar with the data on this procedure. I told her I would ask her oncologist about it, and we'd get back to her.

I called him, and after an exchange of pleasantries, I got down to the matter at hand. "Jenny was in today, and she mentioned that you had suggested intrathecal chemo for her brain metastases," I said. "I told her I'd call to find out what you anticipated from this approach, since this is outside my expertise. What are you hoping we can accomplish with this treatment?"

After a brief pause, he spoke. "It won't help her."

I struggled for a response. "Would you want me to encourage her to go ahead with it anyway?" I asked, finally.

After another pause, this one longer and more awkward than the last, he said, "I don't want Jenny to think I'm abandoning her."

## Policy Checklist

**The issue:** Overtreating patients near the end of life is a major driver of low-value care. To improve the quality of care and reduce costs, future clinicians must be trained in the core skills of care during serious illnesses and near the end of life: communication with patients and families about what matters most to them, expert pain and symptom management, and coordinated care across the trajectory of an illness.

### Resources:

Center to Advance Palliative Care, <http://www.capc.org>; <http://www.getpalliativecare.org>

Vitaltalk, <http://vitaltalk.blogspot.com/>

Oncotalk, <http://www.oncotalk.info/>

End-of-Life Nursing Education Consortium, American Association of Colleges of Nursing, <http://www.aacn.nche.edu/elneec>

Education in Palliative and End-of-Life Care (EPEC), <http://www.epec.net/>

### Related reading:

Back A, Arnold R, Tulsy J. "Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope." New York (NY): Cambridge University Press, 2009.

Back AL, Young JP, McCown E, Engelberg RA, Vig EK, Reinke LF, et al. "Abandonment at the End of Life from Patient, Caregiver, Nurse, and Physician Perspectives: Loss of Continuity and Lack of Closure." *Arch Intern Med.* 2009;169(5):474–9.

Goldstein NE, Back AL, Morrison RS. "Titration Guidance: A Model to Guide Physicians in Assisting Patients and Family Members Who Are Facing Complex Decisions." *Arch Intern Med.* 2008;168(16):1733–9.

Meier DE. "Increased Access to Palliative Care and Hospice: Opportunities to Improve Value in Health Care." *Milbank Q.* 2011;89:343–80.

Meier DE, Back AL, Morrison RS. "The Inner Life of Physicians and Care of the Seriously Ill." *JAMA.* 2001;286(23):3007–14.

things. Most are, in fact, completely untrained in these aspects of the human experience. Medical school and residency have traditionally provided little or no training on how to continue to care for patients when disease-modifying treatments no longer work. Physicians are trained to make diagnoses and to treat disease. Untrained in skills such as pain and symptom management, expert communication about what to expect in the future, and achievable goals for care, physicians do what we have been trained to do: order more tests, more procedures, more treatments, even when these things no longer help. Even when they no longer make sense.

## Training Physicians

So how do we fix this? Most policies to change physicians' behavior have focused on restructuring financial incentives. If we pay more (or less), the theory goes, for certain activities, physicians' behavior will change. The evidence correlating financial incentives and physicians' behavior change is mixed at best, however, and it is too early to judge their impact on patient care quality and costs.

Policies aimed at fundamental change in physicians' behavior will require more than financial incentives. Doctors care deeply about their patients, and most aim to express that care exactly as they were taught to express it. To change behavior, we must change the education and training of young physicians and the professional and clinical culture in which they practice. New doctors should learn about the management of symptoms such as pain, shortness of breath, fatigue, and depression, with intensive training on doctor-patient communication: how to relay bad news, how to stand with patients and their families until death, and how to help patients and families make the best use of their remaining time together. Armed with different training, Jenny's oncologist might have been able to express his care and commitment in ways that better suited his patient's needs.

The Affordable Care Act contains no provisions aimed at standardizing and overhauling undergraduate and graduate medical education. Graduate medical education (GME) funding from the Medicare Trust Fund is the main source

## A New Perspective

His comment struck me. For years I had tried and failed to understand why so many of my physician colleagues persisted in ordering tests, procedures, and treatments that seemed to provide no benefit to patients and even risked harming them. I didn't buy the popular and cynical explanation: Physicians do this for the money. It fails to acknowledge the care and commitment that these same physicians demonstrate toward their patients. Besides, Jenny's oncologist would make no money from the intrathecal chemotherapy procedure. Instead, the impulse motivating him to order more tests and interventions was as an expression of his continued commitment to helping her.

It seemed that the only way Jenny's oncologist knew to express his care and commitment for her was to order tests and interventions. He felt that to stop doing this was akin to abandoning her. His words transformed my under-

standing of what I've viewed as inexplicable behavior in the face of progressive and terminal illness.

It was ironic, as well. The only way in which Jenny felt her oncologist had actually abandoned her, as she told me, was by his unwillingness to talk with her about what would happen when treatment stopped working.

How did Jenny and her oncologist come to see things so differently? Patients and families, especially those dealing with a progressive cancer, know that every life ends in death. They assume their doctors are trained and knowledgeable about end of life, as well, and they assume that if the doctor recommends more tests and treatments, he thinks they will help in some way. Patients and families also assume that doctors will tell them when time is running out, what to expect, and how best to navigate these unknown and frightening waters.

But many doctors don't do these

of financial support for physician training after medical school. At least in theory, policy makers could tie such support to training priorities important to Medicare beneficiaries, such as basic palliative care skills and knowledge.

At present, however, government has few levers to use in influencing the content and quality of physician training. A 2010 report from the Medicare Payment Advisory Commission suggested linking Centers for Medicare and Medicaid Services support for GME funding to the achievement of medical competencies and standards aligned with payment for quality outcomes. Subsequently, a joint initiative by the Accreditation Council for Graduate Medical Education (ACGME) and the American Board of Internal Medicine developed twenty-two training milestones (knowledge, skills, attitudes) to ensure certain competencies for internal medicine residents, such as effective communication with patients and caregivers.

Today, virtually 100 percent of medical school-affiliated teaching hospitals have palliative care teams. Recent data show that the younger the physician, the higher his or her familiarity and comfort with palliative care. Resources for teaching these skills are widely available and could be standardized and scaled to reach all trainees. A working group of the American Academy of Hospice and Palliative Medicine is developing a set of competencies, milestones, and certain essential tasks physicians should know, called “Entrustable Professional Activities,” in palliative medicine for medical residents.

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### **Saying Goodbye**

As we talked, Jenny’s oncologist had a change of mind about his treatment recommendation. “We’re not going to do that,” he told me. He called Jenny and told her that he didn’t think intrathecal chemotherapy would help her and that he thought it was time to involve hospice. Jenny gave up working, entered a hospice program, and settled in at home. There, her husband and daughter, along with the hospice team and I, took care of her.

Toward the end of her life, Jenny told me she wanted to thank her oncologist and say goodbye. Once she began receiving home hospice care, he had neither called nor visited. Her feelings of gratitude and connection to him had only grown as she prepared to die. With her permission, I called him.

“Jenny asked me to call you because she would love to see you,” I said.

“Isn’t she at home on hospice?” he said. “There’s nothing I can do for her now.”

Though he sounded slightly irritated by my call, I thought about how many

such losses he had experienced in his oncology practice and how painful and distressing the prospect of Jenny’s death might feel to him. I persisted.

“She feels very attached and grateful to you,” I said. “She wants to thank you, and she wants to say goodbye. It would be great if you could stop by.”

He had not visited a patient at home before, but he agreed to go. She thanked him for his amazing care and for giving her so many good years after her lung cancer was diagnosed. After that visit, she lived only a few more days.

I am grateful to Jenny’s oncologist for reminding me that the commitment to care and help is behind physicians’ recommendations to their patients—recommendations firmly based on what they learned during their training. Both Jenny and her oncologist wanted to sustain their human connection, the relationship between doctor and patient that is at the heart of quality of care. With the right training and skills, doctors can honor that relationship throughout their patient’s experience of illness, even and especially when disease-focused treatment is no longer beneficial. Our patients, and their doctors, deserve no less. ■

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